PACER REPORTS

Understanding Patient and Family Experiences in the Daily Care of Critically Ill Patients

Marlyn Gill (PACER Lead), Debora Boulton, Donna Oswell and Peter Oxland (PACER Interns)

For the Critical Care Strategic Clinical Network
Alberta Health Services

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PACER[1] REPORTS

Executive Summary

Understanding Patient and Family Experiences in the Daily Care of Critically Ill Patients[2]

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In conducting a study of the gaps in daily care of critically ill patients across Alberta, the Critical Care SCN contracted PACER (Patient and Community Engagement Research Program) to look at what works and what doesn't for Intensive Care Unit (ICU) families and patients. The goal was to involve as many ICUs in Alberta as possible. Thirty-one participants were recruited by patient care managers and staff from thirteen ICU units across Alberta, including both larger urban centres and smaller regional centres.

PACER METHODS

The PACER (Patient and Community Engagement Research) method enables participants to work with patients trained to conduct engagement research that involved three distinct steps: **Set, Collect** and **Reflect**.

Set: In a day-long focus group, participants refined the research direction and questions. The guiding question, *"What happened that made it possible to be or feel involved in your relatives' care?"* revealed that families who experienced a smooth, informed entry to ICU exhibited a higher level of trust and comfort. We therefore used questions about the actions of staff that either increased or decreased trust and comfort in subsequent COLLECT focus groups and interviews.

Collect: During the Collect phase, day-long focus groups were held in Red Deer, Edmonton and Calgary, and, in addition, participants were interviewed individually. All data were transcribed verbatim and analyzed for thematic content.

Reflect: In the final day-long focus group, the themes from the analysis were displayed on a wall with participant quotes reflecting both positive and negative patient and family members' experiences. Each participant reviewed the analyses, added comments and confirmed the themes. We then grouped the themes into an overall interpretation and noted priorities.

WHAT PATIENTS TOLD US

There are three distinct phases in the ICU journey. First, at the time of admission, families are disoriented, in shock and anxious. They value immediate connection with staff, speedy information about patient status, and being able to stay informed and in touch with staff. Next, during their stay, families value immediate connection with staff and staff efforts to lessen the stress of anxiety about their critically ill relative. Finally, the post-ICU period for those transitioning to regular hospital wards is traumatic. Many patients and families are worried about the longer-term effects of the medications used in ICU.

Our data collection focus was the daily care for patients and families, where we identified five main categories:

1. Honoring Patients and Their Voices
2. Needing to Know
3. Making Decisions
4. Culture in ICU
5. Medical Care

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[1] This project has been conducted as a research support function of the Patient and Community Engagement Research (PACER) program at the University of Calgary.

[2] This qualitative study is the patient and family component of the first part of a PRIHS (Partnership for Research and Innovation in the Health System) grant project *Reassessing Practices in the Daily Care of Critically Ill Patients: Opportunities to Identify and Close Evidence Care Gap.*

1. **Honouring patients and their voices:** Many ICU patients have little or no voice when they come to ICU and family members feel responsible for speaking for and about the patient, their preferences and personality. They value staff who listen to family stories and speak directly to the patient as a person. This was key in establishing trust in ICU practice.
2. **Needing to know:** Families who know what is happening and how their family member is doing trust the process and are able to leave the ICU to attend to their own needs and their family. Trust stems from consistent staff contact, regular updates, respect for privacy and the confidence that they will be informed if anything changes.
3. **Making decisions:** Families need to be supported and informed a timely manner, in a safe place and with respectful language especially when discussing prognoses and Goals of Care. The balance of hope and reality in ICU is essential for all families, as this prepares them for situations when patients face imminent death.
4. **Culture in ICU that creates and maintains a community of caring:** While appreciating the hard work, skills and compassion of staff, they noted the fragility of trust which can be broken by one negatively perceived action or statement, no matter what relationship had been previously built. Culture in ICU is the fourth major category, with four sub-categories: Providing Ongoing Access to Support Staff; Inviting Family to be Part of Care Team; Allowing Family to be with Patient as Needed, and the related ICU Facilities for Families, describes how families and patients would prefer the staff to act.
5. **Medical Care**: Medical care was seldom discussed apart from its excellence. However, participants were concerned about information not being transferred at shift changes and they struggled to form relationships with staff because the staff were continually changing.

SUGGESTIONS FOR PATIENT AND FAMILY ENGAGEMENT

The following are the top five suggestions of patients and family members:

1. Provide dedicated team members to liaise with families on a consistent basis. This could include a social worker, ward clerk, chaplain, or designated nurse. The dedicated individual could be a family guide – someone with experience and ongoing availability who is interested in families and able to inform them about ICU practices and language. They would act as guides, navigators, and translators of medical terms as outlined within the findings. This would foster more stable family engagement with ICU.
2. Staff should recognize the fragility of family trust. Unfortunately, the vast majority of caring staff don't make up for the very few who are brusque, inappropriate or leave families feeling a nuisance, vulnerable, fearful or not welcome.
3. Previous studies have stressed the importance of communication as a key factor in maintaining a patient and family-centred ICU. This study confirms this, and stresses the importance of the mode, tone and content of communication.
4. An information sheet summarizing the more common longer-term side effects of the drugs administered in ICU should be provided to patients and families.
5. The 'Transition from ICU to Hospital Ward Study' is a vital component in understanding the difficulties of this transfer. We also recommend that an investigation of post-ICU trauma might be useful. Patient and family lives are often irrevocably affected by the critical illnesses treated in ICU. Thought might be given to an investigation of this phenomenon with a view to identifying those families who may need further help. This may take the form of timely trauma and/or bereavement counseling.

Understanding Patient and Family Experiences in the Daily Care of Critically Ill Patients

Introduction

This qualitative study is the patient and family component of the first phase of a PRIHS (Partnership for Research and Innovation in the Health System) grant project ***Reassessing Practices in the Daily Care of Critically Ill Patients: Building Capacity and Methodologies to Identify and Close Evidence Care Gaps.*** While many advancements have been made in the relationship between patients and families and Intensive Care Unit (ICU) staff since Molter (1979) first introduced the forty-five dimensions of the needs of relatives of the critically ill, it is recognized that not all families, patients and staff are satisfied with the quality of such relationships (Hupcey, 1999).

In an effort to understand both the negative and positive experiences of patients and families with a view to closing any perceived gaps in interactions with ICU staff, Patient and Community Engagement Researchers (PACERs) were asked to undertake this research. PACER is an innovative qualitative method, which utilizes trained patients and family members to engage in research with other patients and families. It was important to allow patients and family members to relate all of their experiences, good and bad, so that we could understand what works for them and what causes them distress and mistrust.

Background and Context

Many studies outline the needs of families with critically ill family members being cared for in an intensive care unit, identifying information, proximity to the patient, assurance, support and comfort as important (Chelsea & Stannard, 1997; Hickey & Lewandowski, 1988; Kleiber et al., 1994; Leske, 1986). Lynne-McHale and Deatrick (2000) have also pointed out the fragility of trust between families and health care providers.

Studies examining the nurse-family relationship (Hupcey, 1998; 1999; Tarnowski & Hanson, 1999) report that both nurses and families may engage in behaviours which cause distancing and, “perhaps at times, hostile interactions between the family and the nurse” (Hupcey, 1998, p. 253). Fox (2014) suggested ICU nurses should be trained in palliative care strategies to engage families, as such strategies would more effectively serve the needs of families. Nelson et al (2010) investigated patient and family definitions of high quality palliative care in ICU. This study used physician-facilitated focus groups using predetermined open-ended questions and probes.

Good communication is recognized as a key factor in keeping families well-engaged with ICU staff. Recent research has focused on the benefits of engaging families in rounds and daily goals of care (Pronovost et al., 2003; Phipps & Thomas, 2007; Jackobowsky, 2010; Cypress, 2012). These studies noted that, while some families have noted improvement, it is not consistent. The principle complaint is a lack of understanding of the medical language used by ICU staff.

Henneman and Cardin (2002) advocate for and describe a family-centred approach in ICUs and believe that no single change or strategy to engage families is sufficient. They promote the formation of an ICU multidisciplinary team who understand, support, and are responsive to family needs. They suggest reliance on nurses and/or physicians to maintain such connections is unrealistic, as they may not have all of the skills necessary to provide such service, and in addition, this may place an unnecessary and often inappropriate load on them.

Methods

PACER uses several qualitative research methods set within the patient engagement research framework outlined in *Grey Matters* (2010). For this project we integrated a phenomenological perspective (Patton, 1990; Bogdan & Taylor, 1975; Lincoln & Guba, 1986: Kirk & Miller, 1986; Berg, 1989) with the patient engagement research methods we use to conduct patient-to-patient studies. This method was chosen as we wished to explore the experience of patients and families in the intensive care setting. Our purpose was to determine, '*What works and what doesn't work for families and patients who are in ICU?'*

Recruitment and Inclusion Criteria

We contacted all 14 ICUs in Alberta requesting their help in recruiting participants. Thirty-two participants were recruited by Patient Care Managers, social workers, physicians, and other staff from 13 ICU units across Alberta. The ICUs included large urban and smaller regional locations. All 32 participants were Caucasian, spoke fluent English and had education levels ranging from some high school without graduation, to having post-graduate degrees. Participants were recruited using the following inclusion criteria: family members and patients self-identifying as having ICU experience, were over 18 years of age, and spoke fluent English. We diversified our sample by including people with a variety of ICU conditions and outcomes.

Table 1. *Research Participants.*

Code #	**Gender**	**Age**	**Patient or Family**	**First time in ICU**	**# of Previous Experiences**	**Relationship to Patient**	**Hospital**	**Length of Stay in ICU**	**Length of Stay in hospital**	**Home City**
S1	F	46	Patient	Yes	NA	NA	FMC	7 days	16 days	Calgary
S2	F	37	Family	Yes	NA	Spouse	PLC	10 days	3 weeks	Airdrie
S3	F	50	Family	No	1 x Family	Spouse	PLC	13 days	1 month	Airdrie
S4	M	59	Patient	No	2 x Family	NA	PLC	13 days	1 month	Airdrie
S5	M	42	Patient	Yes	NA	NA	PLC	10 days	3 weeks	Airdrie
C1	F	53	Family	No	1 x Family	Spouse	RDRH	3 days	8 days	Ponoka
C2	M	58	Patient	Yes	NA	NA	RDRH	3 days	8 days	Ponoka
C3	F	63	Patient	Yes	NA	NA	RDRH and Ponoka	9 weeks	14 weeks	40 km east of Ponoka
C4	M	69	Family	Yes	NA	Spouse	RDRH and Ponoka	9 weeks	14 weeks	40 km east of Ponoka
C5	F	53	Family	No	5 + (Adult and Ped)	Mother	RDRH and U of A	6 months	6 months	Lacombe
C6	F	59	Patient	No	4x	NA	Fort McMurray, Grey Nuns	4 weeks	5 weeks	Sherwood Park
C7	M	71	Family	No	4x	Spouse	Grey Nuns	4 weeks	5 weeks	Sherwood Park
C8	M	53	Patient	Yes	NA	NA	Grey Nuns	70 days	4 months	Edmonton
C9	M	75	Patient	Yes	NA	NA	Grey Nuns	5 days	3 weeks	Sherwood Park
C10	F	48	Family	Yes	NA	Daughter	Grey Nuns	5 days	3 weeks	Sherwood Park
C11	M	65	Family	Yes	NA	Spouse	Sturgeon, Royal Alex & U of A	214 days	281 days	Lamont
C12	F	65	Family	No	1x	Spouse	Mazankowski	3 weeks	6 weeks	Edmonton
C12a	M	65	Patient	No	1x	NA	Mazankowski	3 weeks	6 weeks	Edmonton
C13	F	50	Family	No	5x	Wife	U of A	1 -3 weeks	Varied	Edmonton
C14	F	57	Family	No	2x	Daughter	FMC / Rockyview	2 weeks 10 days	34 days	Edmonton
C15	F	43	Family	No	3x	Daughter	Lethbridge R H & FMC	105 days	105 days	Calgary
C16	M	67	Family	No	1x	Brother in law	Rockyview & FMC	3 weeks	3 weeks	Cochrane
C17	M	50	Family	Yes	NA	Husband	FMC	21 days	3 months and ongoing	Carstairs
CI 1	M	45	Family	Yes	NA	Father	FMC	2 weeks	2 weeks	Calgary
CI 2	F	67	Patient	Yes	NA	NA	RDRH	6 weeks	2 months	Red Deer
CI 3	F	71	Family	No	1x	Spouse	Royal Alex	2 weeks, still there	2 weeks, still there	Edmonton
CI 4	M	52	Family	No	1x	Husband	QEH Grande Prairie	5 weeks	13 weeks	Clairmont
CI 5	F	49	Patient	Yes	NA	NA	Grey Nuns	6 weeks	9 weeks	Edmonton
CI 5a	M	52	Family	Yes	NA	Husband	Grey Nuns	6 weeks	9 weeks	Edmonton
CI 6	F	37	Family	Yes	NA	Husband	Med Hat, FMC	24 days	5 months	Calgary
CI 7	M	56	Family	No	1x	Wife	FMC	6 days	6 days	Calgary
CI 8	F	55	Family	Yes	3x	Sister	FMC	25 days	25 days	Calgary

Data Collection and Analysis

We collected data using the PACER framework, which consists of three phases: SET, COLLECT and REFLECT.

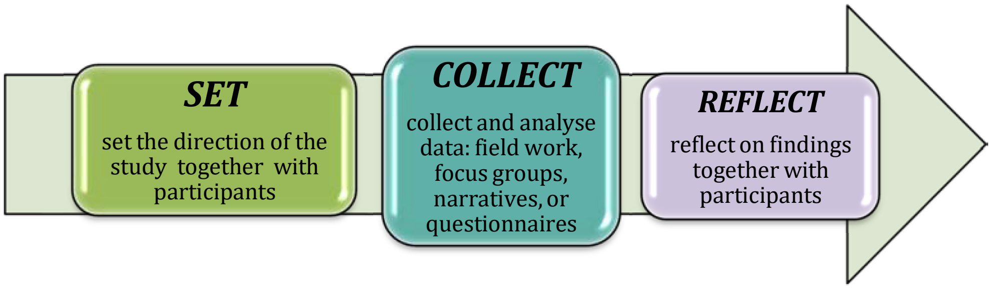

Figure 1. PACER Research Method

SET

The five-hour SET focus group, held in Calgary, consisted of five patients and family members who were asked to share their experiences in ICU. The session was audio taped, and flip chart notes and process recording notes were taken. We asked four guiding questions during the focus group:

1. Tell us what happened that made it possible for you, as a family member, to be or feel involved in your relative's care.
2. What did you find most helpful as a patient or family member?
3. Was there anything as a patient or family member that you did not find helpful?
4. Do you have any thoughts on what would have been better for you as a patient or family member?

After the participants shared their experiences, the flip chart notes were posted on the walls and participants individually identified which topics were most important to them. We discussed these in detail and gathered more information by asking probing questions.

Before proceeding with the COLLECT phase, the flip chart notes, in conjunction with the audiotape and process recording notes, were analyzed to identify the major themes. (Note: we did not transcribe and analyze the SET group audiotape until we had completed one COLLECT activity.) This analysis allowed us to set a direction for the COLLECT phase, ensuring that our guiding questions were related to information our SET participants had identified as most important. In patient engagement research it is the participants, rather than the researchers, who determine the direction of the study.

COLLECT

We held three COLLECT focus groups, one each in Red Deer, Edmonton and Calgary, and interviewed eight participants from several locations in Alberta. The participants had experienced care in 13 ICUs across Alberta.

Using the information gained in the SET focus group, we invited participants to tell us about their experiences in ICU. Our SET participants had identified communication and how staff interacted with family members and patients as being key to decreasing anxiety. Using this information the refined guiding questions for the families were:

1. Tell us about your experiences in ICU that made it possible for you to feel involved in the daily care of the patient.
2. Were you kept updated on any changes in the patient's health? If so how was this done?
3. Were you given enough information about the daily routine in ICU or were you sometimes asked to leave without knowing why?
4. Did you feel part of the "care" team or did you sometimes feel in the way?
5. Is there anything you would like to be done differently that would have been more helpful for you?

The guiding questions for the patients were:

1. How did you communicate your needs to the staff?
2. Were you given any information on what to expect when you got home? If so, was it useful?

At each focus group and during each interview, we asked the participants to identify the issues that were most important to them.

The COLLECT focus groups and interviews were audiotaped and transcribed. The flip chart notes and process notes were transcribed. Phenomenological reduction was used in the analysis of all four types of data (Patton, 1990). The first step in this process involves the "bites" of information in the transcripts being sequentially numbered and coded according to emerging themes. Each theme described or recounted similar types of situations or experiences encountered by patients and / or family members while in ICU. We reached saturation (Glaser & Strauss, 1967) after holding three COLLECT focus groups and four interviews. However, we continued to interview until we had representation from as many regional hospitals as possible.

REFLECT

The REFLECT phase is a form of member checking, as all REFLECT participants had previously participated in a focus group. The member check invites the participants to review the analysis to ensure it accurately reflects their experience and is the final process in phenomenological reduction. We posted all the themes identified in the COLLECT phase (see Figures 2, 3 & 4) on the wall with an explanation of the theme, together with associated positive and negative participant quotes.

Each participant reviewed the analyses and confirmed the relevance of themes. Collectively, we grouped the themes into categories and sub-categories. Each participant then prioritized the importance of the larger categories and we discussed the prioritization until we reached consensus and chose appropriate names for the larger categories. The process of co-creating findings separates PACER from more traditional qualitative research methods.

Following the REFLECT focus group, transcriptions of the audiotape, flip chart, and process recording notes, as well as photographs, were used to analyze the information we had gained from REFLECT participants. We also emailed diagrams of the findings to a representative selection of participants, who all agreed with our analyses.

Research Credibility and Trustworthiness

We used several strategies to ensure the credibility and trustworthiness of the research. First, the patient or family member researchers facilitating the groups, interviewing participants and analyzing the data are the research instruments in the study and each researcher had to understand, reflect on, and state his/her biases (Bogdan and Taylor, 1975; Kirk & Miller, 1986; Patton, 1990, Morse et al., 2002). Second, as patients or close family members of patients, we had a familiarity with the experiences of the participants (Shenton, 2004). Third, we discussed the emerging data, coding, and categories with research colleagues from the larger project working group, academic supervisors from PACER and peers (Lincoln & Guba, 1986, Shenton, 2004). Fourth, we used member checks (REFLECT group and emailed diagrams) to ensure that the analysis accurately reflected participants' experiences. Fifth, we employed iterative questioning, triangulation, thick description of ICU experiences and, finally, completed a literature review to assess the congruence of our findings with previous research (Berg, 1989, Guba & Lincoln, 1986; Morse et al., 2002; Shenton, 2004).

Findings

We asked participants to share their experiences in ICU, and we captured both positive and negative information in each category and sub-category. The negative comments relate to what patients and families would have preferred to have had happen, while the positive comments tell us what went well. Participants and researchers identified three phases in the ICU experience, each with discrete categories and /or sub-categories.

Phase I. Admission to ICU consisted of 3 categories.
Phase II. Daily Care for Patients and Families in ICU consisted of 5 categories with 14 sub-categories.
Phase III. Post-ICU Experience consisted of 2 categories.

Phase I. Admission to ICU

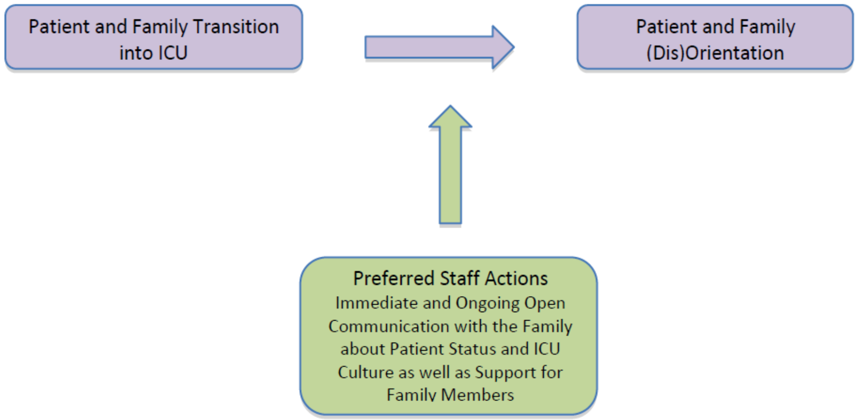

Figure 2. Admission to ICU.

Category 1: Patient and Family Transition into ICU

Patients and families identified that the transition into ICU could be either fraught with difficulties causing high anxiety, or occur in a supported, openly informative and caring manner, lowering stress levels. One husband related how his wife was transferred out of a small hospital to the regional ICU, saying:

> *"So when they transferred her out of […], they didn't know what was wrong with her and we got here (regional ICU) at 2.45 pm, but she was in so much pain – terrible pain ... she was moaning and hurting ... but it was 7.30 pm before a doctor even looked at her and 11.30 pm before she was transferred to ICU and they started working on her. Me and my daughter were here and we never had a clue what was going on neither."* (C4)

The wife of a patient who had gone into surgery and was expected to go to ICU post-surgery became extremely anxious and agitated when, six hours into the surgery, she could find no-one in Pre-Op, ICU, Recovery, or Surgery who knew where her husband was:

> *"So you are just left in the dark after six hours – it's like, okay, where do I go… I'm by myself ... your mind goes to a bad place and I'm thinking to myself, if something happened to him, how would they find me, how would I know if he's okay?*" (C1)

Those relatives who had travelled a long distance to be with the patient and arrived a few days after admission were in the same position as those who were present at admission initially. They needed the same reassurances and updates from the staff who, as they perceived, were "*kind of look at you thinking, 'don't you know'?"* (CI 8)

Other patients and families recounted how well the transition had gone. They had been informed about what was happening and were supported throughout the process:

> "*We moved ICUs and everything, even the nurses, came with us in the ambulance. Both*

> *times two nurses attended with the ambulance people."* (C 14)
>
> "*So we were told what I had and where I would progress to."* (C 8)
>
> *"The whole thing was just done perfectly – how he was transferred from […] ICU to […] ICU, people took care of us totally*." (C 6)

These illustrate successful, lower stress transitions that families found helpful.

Category 2: Patient and Family (Dis)Orientation

Even families and patients whose transition into ICU had gone smoothly described their disorientation in ICU: **"***You don't know what you are supposed to do or allowed to do or say. It's like you are in another country, almost … one day he was shoveling the driveway, then…"* (S 2)

All family members described the shock: "*We all go into shock. Like I wasn't thinking coherently for the first number of days because I was just in shock."* (S 3)

Families were fearful for the patient and because they did not know what to do:

> **"***I got up there. They had not stitched her up and her head was like a volley ball – multiple skull fractures – it was like, oh my God."* (C 17)
>
> "*They didn't really explain what was going on, no doctors, nothing … and they didn't explain, the rules weren't laid out for us at all."* (C 14)

All family members remembered the panic and the disbelief when they learned their loved one had been admitted to ICU. They wanted ICU staff to understand they were reeling and trying to grasp the reality of their situation. They were not in a position to ask coherent questions and needed proactive engagement.

Category 3: Preferred Staff Actions

Family members were very clear about what ICUs could do to lessen the initial shock and trauma of having a critically ill family member. Those families who had a contact person in ICU to explain things to them slowly and calmly found they were less disoriented than those left to fend for themselves:

> *"I was met by the unit clerk and introduced to the ICU. He took me around and said to me 'this is where the refreshments are, this is how you get into the room, this is what you do' ... besides the shock and wonder, I was taking all this in and thinking that I don't have to ask these questions because this man is showing me everything ... and so I found that to be incredibly helpful."* (CI 3)

In contrast, some families recounted "*buzzing or phoning to get in to the unit and being told to just wait"* (CI 8) by a curt disembodied voice. Some relatives waited for up to ten minutes before being allowed in: their fear, anxiety and mistrust increasing with every minute. Families often reiterated how useful it would be to *"have another layer (of staff) that deals* *with only family."* One wife described this need:

> "*It's almost as if everything is going on and someone is standing in the background saying 'hey, it's okay.'. . Like we are two birds on a wire. They can walk you through it instead of letting you just hang out. Maybe if you had a kind of guide, maybe between two patients and you could ask some questions because the nurse is really busy. Instead of pulling the nurse and the nurse sighs. If there were someone who could just explain the scenario and what's going on ... tell you they are going to do this because of that ... let the nurses and doctors do their thing."* (S 2)

Many focus group and interview participants voiced the need for a person dedicated to working on a daily and ongoing basis with the family. This would result in less trauma and more trust. Families would like a guide to be able to "*ask when you don't understand what they (medical staff) are saying, someone who knows the meaning of those words. What a difference that would make."* (S 3)

Phase II. Daily Care for Patients and Families in ICU

The second phase of the ICU journey consists of five main categories:

Category 1: Honouring Patients and Their Voices (What patients and families need from staff)

Category 2: Needing to Know (What patients and families need from staff)

Category 3: Making Decisions (What patients and families need from staff)

Category 4: Culture in ICU (Proactive actions from staff to patients and families)

Category 5: Medical Care (Patient and family experiences of medical care)

Our participants believed that, when their perceived needs were met, they developed Comfort and Trust in the staff and were able to see themselves as part of A Community of Caring. When staff acted proactively to promote a "welcoming" culture in ICU, which participants considered Appropriate Interaction, they believed staff was inviting them into A Community of Caring. Medical Care, in their view, fed directly into the formation of A Community of Caring (see Fig.3).

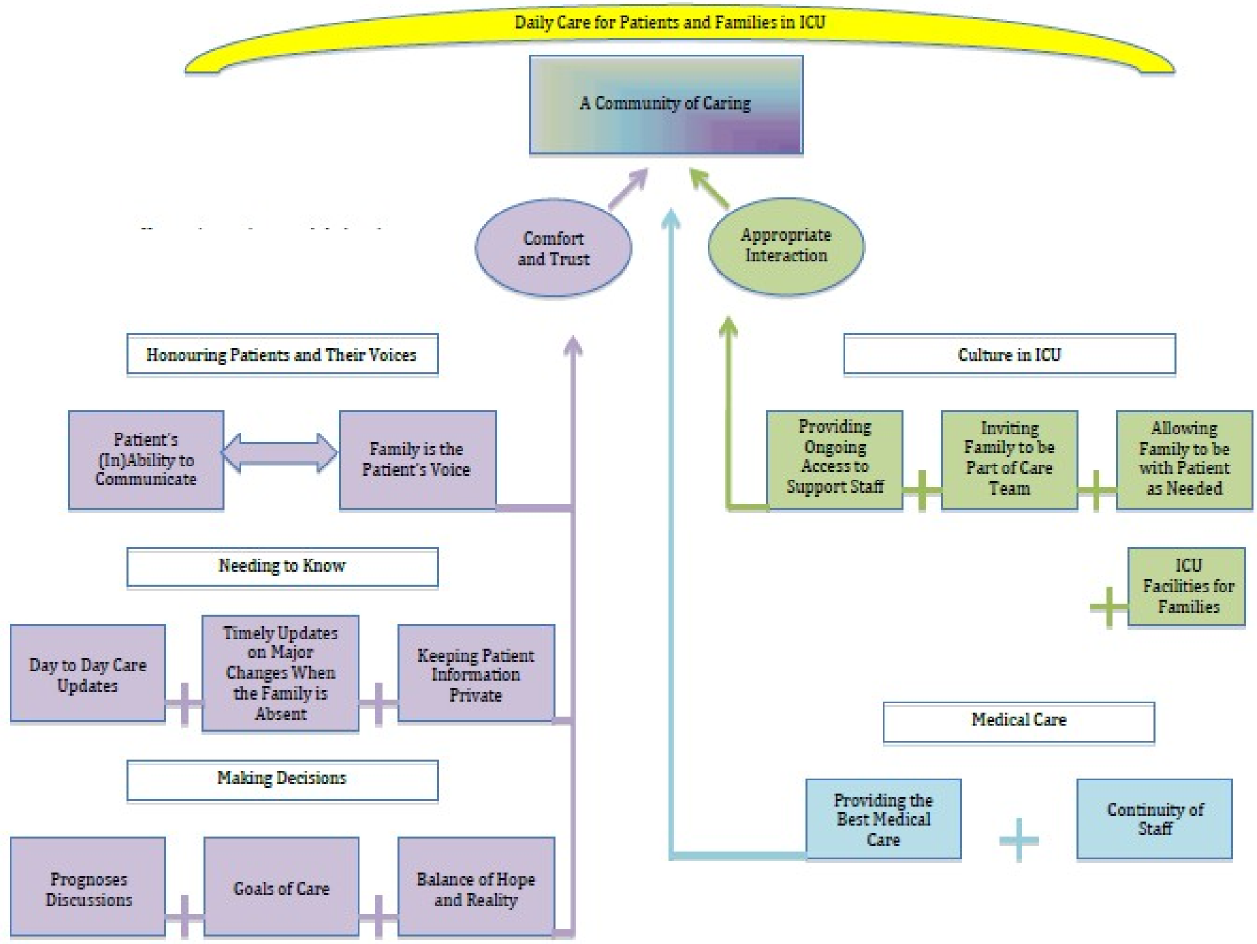

Figure 3. Daily Care for Patients and Families in ICU.

As can be seen in Figure 3, we identified, with the help of our REFLECT participants, three categories, illustrated in descending order of importance, that patients and families perceive as being important to build comfort and trust within the ICU:

1. Honoring Patients and Their Voices
2. Needing to Know
3. Making Decisions

Category 1: Honouring Patients and Their Voices

Honouring Patients and Their Voices, identified by patients and family members as the most important category in this stream, has two sub-categories:

a. Patient's (In)Ability to Communicate

b. Family is the Patient's Voice. The two themes are interconnected, as many ICU patients have little or no voice at the beginning of their stay in ICU and rely on family members to speak on their behalf, as well as describes who the "patient" is, as a person.

a. Patient's (In)Ability to Communicate

The personalization of comatose patients is extremely important to family members. One participant recounted how difficult the family found it to discover that "*her brother's white board was bare, apart from some medication information"* (CI8).

All the other patients' boards had personal information about the patient that was changed daily. She perceived that her brother was a patient rather than a person. Everyone agreed that they appreciated and felt more trusting and comfortable when staff treated their relatives as a person, with a life and personality, by talking to their unresponsive relative:

> *"You know it means a lot to the family when the nurses keep calling the patients by name and tell them what they are going to do. It was like 'Y' is doing good today and 'Y' will be this and 'Y' will be that. It was the personalization – this is your husband – 'Y'."* (S 3)

Another participant related how much it meant when *"they asked me to bring in a photograph of 'P' so they could know who she really is".* (C17).

Others were told to bring in the patient's favorite music or some personal belongings. One participant summed it up: *"In ICU you are a person, not a patient"* (C2).

b. Family is the Patient's Voice

Family members expressed the overwhelming sense of responsibility they experienced to act as the patient's voice:

> *"I often woke up and felt so alone. I was the family spokesman for my husband and did all the communicating for him ... as spokesperson, I felt I was my husband's voice, a huge responsibility. I would love to have known what to ask. ICU was like walking in to a whole different world* and *it was difficult being L's voice ... it's like oh my God, I'm speaking for him, he can't speak for himself, it's a huge responsibility ... you have to be right there, you have to be the one talking to the doctors."* (S 3)

The daughter of a semi-responsive patient explained:

> *"I had one bad experience where I was literally thrown out of the room by the doctor who did not let us attend rounds. My dad was not answering his questions and I said 'dad you need to answer' and was promptly told to get out. When you are in a fragile state after 108 days it's not how you want to be treated by anyone. I felt he took the patient's voice away from me and chased me out."* (C15)

Sometimes when family members tried to give the physicians information about the patient, they believed they were dismissed:

> "*I explained to them that 'T'. was on Remicade, which is an experimental drug for colitis and that antibiotics shouldn't be used. I was told 'right now we are saving his life' ... and he did have a bad reaction."* (C 12)

When staff wanted to extubate an MS patient who had coughed once, his wife told us:

> *"They weren't really listening to what I was saying - that, because of the underlying fatigue, the one cough he had doesn't really mean anything ... as it turns out they had to re-intubate him."* (C13)

The common consensus among participants was:

> "*Family knows best what's going on for the individual patient (from a personal perspective) ... you know the person, but that ability to communicate that can be a challenge unless you bully yourself into telling them."* (C17)

Some families found that they were interpreters for patients even when the patients regained consciousness but were still intubated. Patients found communicating their needs to staff members very difficult:

> *"When I woke up ... I was strapped down, my legs were strapped too. I had no idea what was going on. I needed to go to the bathroom badly and my bed buzzer was gone. It was pitch black; I woke up and had the tubes in there. I started kicking the bed, nothing happened, I flicked off the oxygen sensor and the alarms went off. The nurse came in and she goes 'you better not be doing that, that's not good,' and she put it back on and walked out*." (S 5)
>
> *"The nurses kept saying 'I don't know what you need or want.' If it hadn't been for my sister asking like, 'are you hot, are you cold, do you need repositioning, are you itchy', and she would just keep going until I nodded. No one else did that."(S 1)*

Other patients had very different experiences:

> *"You only had to push the button once and someone was there within 30 seconds"* (C3)
>
> *"It was like being in a fish bowl. I just had to twitch and eyebrow and they'd be there."* (C2)

All participants, however, expressed that family was very much the interpreter or go-between for the patient. Many patients and families did note that there were some aids for communication such as white boards or cards with pictures, but patients often couldn't use them effectively:

> *"When I was in ICU, I couldn't hold on to a marker, my hands were swollen so bad I couldn't bend them; I was 100% paralyzed ... there was no communication. They gave me this piece of paper with the alphabet and I'm using my eyes to spell ... Do you know how long it took me to spell out my foot's caught (in the bed-raising mechanism)? "*(C 8)

We were also told fear was a huge factor when patients were in ICU, and it was very difficult to communicate this to lessen their fear:

> *"Fear is huge in hospital ... that's why I didn't sleep. I was scared to go to sleep. I didn't know if I was going to wake up. You know that drug that killed Michael Jackson, they*

> *had me on the drip with that stuff and I still didn't go to sleep."* (C 8)

Several families and patients found iPads very useful and recommended ICU's should use these devices when patients cannot speak or write. Patients and their families believed having the patient's voice heard, and acted upon, was of primary importance in their struggle to become comfortable and trusting within the ICU.

Category 2: Needing to Know

Needing to Know, the second main category, involved staff satisfying the family's need to know the patient status, which gave them some sense of control over the situation. We identified three sub-categories within Needing to Know:

a. Day to Day Care Updates

b. Timely Updates on Major Changes When the Family is Absent

c. Keeping Patient Information Private

a. <u>Day-to-Day Care Updates</u>

The degree to which family members were informed about patient status varied enormously and ranged from being given little or no information to receiving substantial information. Families who had good knowledge of day- to-day (and even moment-to-moment) activities appeared to be much more comfortable in ICU and more trusting of the staff than those who had less knowledge/information:

> *"They didn't tell me a lot of what was going on ... I wanted to know, hear the truth, options, alternatives not just 'it's day to day.' That means nothing."* (S 2)
>
> *"But I found that if I didn't ask questions, I didn't get answers, and they didn't volunteer what was going on. I mean even to get 'he slept through the night' and stuff. It would have been great to have a schedule – 'this is when we are bathing him, this is how long it will take' ... 'this is kind of the schedule – this is the goal for the day.' I would have known what was going on ... not just sat in the waiting room and think, okay it's been 20 minutes, what's going on?"* (S 3)

The families who were kept well informed were more relaxed:

> *"We always knew what was going on ... they were clear about what they were doing and why and what they intended to do next... I was always in the know as to what they were doing and why and we knew his condition daily; the doctors would always let us know what was coming up and they would tell us. So, in my mind, it was always clear as to what they were doing."* (CI 1)
>
> *"We were told 'here's what we doing and the plan of the day' and that helped a great*

> *deal, so we just waited for the doctors and their plan for the day."* (C 14)

b. Timely Updates on Major Changes When the Family is Absent from ICU

Families expressed a great need to have timely updates on the patient, especially if there was a major change in their absence from ICU. We were told about the benefits when there were timely warnings, or the distress caused when relatives came into the room and were faced with a major downturn:

> *"When 'X' got up to ICU, I went home … I slept for about two hours and then phoned. I couldn't get hold of a nurse so I went to the hospital. I found him in a coma; I wasn't told ... it was a huge shock. I felt like I missed, I felt like I should have been there. Like I left the hospital and they didn't phone me ... I was gone for a few hours and when I came back it was like 'what happened'?"* (S 3)

We also heard stories describing timely calls and staff empathy: "*I got a call at five o'clock in the morning that she had started to hemorrhage, so we went back into ICU and the staff was just wonderful*" (C 4).

If families believed they would be informed of a major change, they developed trust in the staff: "*You could put your trust in them and then they earn your trust*"(C 3).

Families who did not get updated did not develop this trust, and felt they needed to remain close to the ICU: *"(We) took over the waiting room and camped out ... always at least four of us sleeping over"* (C 10).

c. Keeping Patient Information Private

While not all participants mentioned the importance of keeping the patient's information private within the immediate family, they agreed this was vitally important. One participant spoke about the challenge related to patient privacy: "*Someone, not part of the family, would arrive and the nurses would give them information about my husband. This upset us a lot."* Participants were concerned when people phoned the ICU and were given information without their knowledge. One participant suggested that all ICUs should follow the practice of a pediatric ICU where her son had been a patient: "*Each family had a password number and they could not enter ICU or get phone information without it*." In contrast, now that her son is an adult, neighbours were able to call the ICU, obtain a report, and share private information about her son with other people in her small community. In some cases, staff members passed along patient information to mutual friends:

> *"One of the people on staff knew me and knew of an ex-family member, who knew my ex-wife. I got a call from my ex-wife ... from Arizona saying, 'I heard Y was in hospital' ... that was a huge breach of confidentiality ... that was bad, it was a shock."* (C16)

These breaches of privacy appeared to distress families and lower their trust.

Category 3: Making Decisions

Making Decisions is the third major category in the patient's and family's perceived needs that fosters the development of comfort and trust. Families need to be supported and appropriately informed when making any decisions about patient treatment. The timing, place, and manner of sharing this information are crucial, especially when life and death decisions are being considered. We identified three sub-categories in Making Decisions:

a. Prognoses Discussions

b. Goals of Care

c. Balance of Hope and Reality

a. <u>Prognoses Discussions</u>

Prognoses discussions was an important topic, regardless whether the patient lived or died. We were told that prognoses discussions usually take place in family meetings, especially when the family has to make decisions around the removal of life support. However, we were also told that sometimes families believed these discussions or statements were inappropriate, in both the time and place of discussion. Several families explained that physicians had talked about removing life support in patient's presence, but did not include the patient in the discussion. One husband related his wife's physician saying:

> "*She will probably have to go to a nursing home, so why not just let her go?"* (C 4)

The mother of a patient was told: "*You know it just doesn't look good and we should be thinking about maybe pulling the plug or whatever*" (C 5).

Others cited hallway conversations they perceived as inappropriate, extremely hurtful, and distressing:

> "*We stood outside her room and he said 'she isn't going to make it through tonight.'*" (C 11)

> "*We were all in the hallway and he said to my daughter 'your mother has a 5% chance to make it through the night.'"* (CI 4)

While all families said they valued honesty, they also needed to be respected when bad news was being given. Families found that prognoses with no explanation were useless and anxiety provoking:

> *"One doctor said her chance of survival at six months was 30%. In context she had no idea what she was talking about, because we had no idea what the extent of the injuries were and what the ramifications would be."* (C17)

Family members faced with making life and death decisions, complicated by quality of life issues, indicated they might not have been as well informed as they would have liked. One participant acknowledged that physicians tried to help but he was left with "*huge uncertainty"* when told:

> "*There are non-catastrophic brainstem injuries as she is still here, but we don't know what the implications are.*" His greatest anxiety and fear was: "*(Getting) into a place where we couldn't back up the bus ... if we got into a situation where my wife would never want herself to be in.*" *(C 17)*

Participants voiced their perception that ICU is more focused on saving lives, and that more time, input, and thought from various medical perspectives might be useful when considering post-ICU quality of life implications. Families were making choices that could have severe consequences, changing the direction of both the patients' and familys' lives forever, and needed to be able to review their options from multiple perspectives.

Many families praised the clarity they received in family meetings:

> "*The doctor said ... 'I have done everything I can do but I am going to bring in someone else to review', maybe he has missed something. He came back later and said 'no he was not going to survive it.'*" (C 16)

Others found the meetings very distressing, as they had no idea of the severity of the topics being discussed:

> *"There were lots of family meetings, which caused a lot of anxiety. I never knew the severity of what we were discussing. Is this a 3 meeting or is this a 10 meeting ... it would have been nice to know because every time they called a meeting we would absolutely panic because we did not know what the meeting was about ... we would have liked a written report ... I had been in ICU six weeks with him before I knew what his most severe issues were*." (C 15)

b. <u>Goals of Care</u>

Goals of Care designations encompass the experiences of participants who had to make decisions around removing life support. Participants told us when and how the reasons for such decisions were explained by, and discussed with, physicians was of utmost importance. Those participants who believed end-of-life discussions had been handled well were mostly familiar with the Goals of Care designations, where everything had been carefully explained to them. In contrast, while some participants who had never heard of the designations were happy, accepting that their relative had "*reached the end of the road,*" others were very upset. One partner, whose husband survived, explained:

> *"He wasn't responding the way the doctors thought he should have been so we had a family meeting to discuss what he would want done ... we decided, his mother and me, that he would want everything done unless there was no brain activity. About five days after this meeting, I was throwing my gloves in the garbage and I saw a piece of paper that had DNR on it ... I thought it must be another patient's ... I turned it around and it had his name on it ... we had never said – it was probably the worst experience."* (C 13)

Other participants agreed with her belief:

> "*If it's decided that's what we are going to do or not, something should be signed. It was all verbal, no one ever said he was going to be a DNR, but in this doctor's head, that's what he read."* (C 13)

Families who perceived they had been given good information said:

> *" I am familiar with the Goals of Care and they brought it up right away with our family ... you decide which level you want to be at, the doctor signs it and you get it when you go home."* (C 11)

Other patients had a living will to guide their family. Along with an understanding of the Goals of Care designations, these families appeared to be the most satisfied:

> *"At one point I asked the doctor, I understood the percentages, but where does it become that she is on total life support? He told me ... and I said we are getting awfully close to that ... we have signed papers that she does not want to be resuscitated."* (CI 4)

This participant had sadness in his voice, but he had the comfort of knowing he had made an informed choice supported by his wife's physicians. This comfort appeared to be important for families both at decision time, and later as they reflected on their choices.

c. Balance of Hope and Reality

Balancing hope and reality is important to all families with relatives in ICU, but becomes crucial when a patient faces imminent death. When participants thought they were not being told the truth with respect to the seriousness of the illness, they said their fear and anxiety increased:

> *"They wanted to make it not as serious; they wanted to tone it down for me ... in some ways they tried to minimize, just so it didn't sound so serious. But I knew it was serious ... so why are you not telling me it is serious? "* (S 2)

Conversely, another family member's experience was:

> *"We pretty much knew he wasn't going to make it, but nevertheless I felt ... I was being supported by the hopeful behaviours and demeanors that the healthcare professionals had for X. It made it easier to visit him when these people were there."* (CI 1)

Although a father knew his comatose son was dying, he explained: "*There was never like a gloom and doom attitude ... the nurses got to know his name and they talked to him ... it was very personalized.*" We were told that "*hope management ... is an area that is absolutely critical ... managing palliative care and talking about palliative care in ICU is really critical."* One participant summed it up saying:

> "*Another excellent thing was they left hope – they didn't come in and say 'this is it; she's not going to make it.' They said this percentage or that, they told us what is or is not happening, so they did a really good job with hope and yet they were realistic."*

Category 4: Culture in ICU

Culture in ICU is the fourth major category, with four sub-categories:

a. Providing Ongoing Access to Support Staff
b. Inviting Family to be Part of Care Team
c. Allowing Family to be with Patient as Needed
d. ICU Facilities for Families

Each sub-category describes how families and patients would prefer the staff to act.

a. <u>Providing Ongoing Access to Support Staff</u>

This service was reported as a 'hit or miss.' Participants had varying degrees of success in their interactions with support staff including social workers, respiratory technicians, and pharmacists, as well as with spiritual services. Their experiences ranged from absolutely no contact, to the development of meaningful supportive relationships:

> "*Social worker, my husband never mentioned one, where did you meet her?"* (S1)
>
> "*The support from the social workers was incredible, they were helpful in facilitating contacts, meetings, everything."* (C 16)
>
> "*On Sunday this person showed up and said 'I'm looking for Y', took me into the quiet room ... had she not come to get me I would not have reached out. Proactive activity on her part was really good, she has been a real resource to me."* (C17)

The families' perceptions of proactive support were staff-specific rather than related to the overall experience within an ICU, and ranged from disinterest through to proactive engagement. We were told about a variety of experiences:

> *"They gave me a package of stuff. Here's where you find this or that ... she made sure I knew where the parking was and the bathrooms and asked if I was going to read the package*. " (S3)
>
> *"He didn't just make initial contact and said 'if you need me give me a call', and handed us a business card, like that's the wrong way to go about things. They would come round to see how things were going and they balanced that with being in your face all the time*." (C 17)
>
> *"I felt like I was imposing on him ... I was afraid to knock on his door. He was never on the unit, whereas the other social worker ... was moving around introduced herself to me said 'hi what can I do for you, do you have any questions?' She was amazing, totally amazing."* (C 10)

Support staff that engaged families on a personal and almost informal level appeared to be well received by patients. Participants stressed the importance of staff initiating the invitations as they told us that they were hesitant and did not know what they could or could not do, or even if they should do anything.

b. Inviting Family to be Part of Care Team

This important invitation satisfied the great need family members voiced to be included somehow in the care of their relative:

> *"I wanted to be involved but I guess I was more of a burden with them ... I'd ask and you would get the sigh ... you just want to be there ... you don't want to get in their way either (medical staff) ... there is an awkwardness ... I felt there was a coldness to ICU. The reality is ... you don't feel part of the team, there's just something missing."* (S 3)

In contrast to such experiences, others told us:

> *"I can honestly say that we have always felt part of X's care team, that our opinion really did matter and that they valued what we had to say. They always say to us 'you know him best, you know what works so if anything seems a bit off. We will look into it ... we have always felt respected and that's a big thing."* (C 5)
>
> "*They told me to watch for certain things … and if you are seeing anything different let us know. I was very much invited to be involved.* " (C 1)

Families believed that when staff invited them to become involved, they could have the closeness and sense of helpfulness they needed. Feeling part of the care team appeared to give family members a sense of some control over a frightening experience.

c. Allowing Family to be with Patient as Needed

Families believed being close to the patient was important, especially at the beginning of an ICU stay or if they had insufficient trust and confidence in staff members whom they perceived were not looking after their relative as well as they would like. When nurses repeatedly told family members to *"take a break because he'll need you when he wakes up"* (C10), the family's common response to being away from the bedside was: *"if you know what's going on it helps some of your fear ... I'm thinking I want to be here"* (S2).

At that moment in time, families are not really capable of looking down the road or seeing the value in saving their energy. They need the reassurance of being present:

> *"Any change to those monitors I was right there asking 'is this a problem?' That's how I got to know all about the numbers. It almost felt like you had to be responsible for that too; you don't want to miss it."* (S3)

We were told about a daughter, rebuked by a nurse for asking about the numbers, being told: "*'Don't worry about that, that's our job.'"* She told her mother *"I felt so pushed aside"* (S 3). Others, however, who had developed a trusting relationship with staff said: "*It was good to go home and unwind, as I knew she was in good hands"* (C 2). They were confident that they would be called or could call in at any time so had less need to be always present:

> *"If I was at home and woke up in the middle of the night and just be anxious, I could phone … and get right through to X's nurse and there she is. She is looking at X while she is talking to you and you just feel – you know."* (C 5)

Families who had difficulty getting a response, or had a sense they were being a nuisance in response to phone calls, told us they did not like leaving the ICU. They were similar to the daughter who told us: *"My brothers and I, we slept there every night"* (C10).

Closeness to patient seemed to decrease the anxiety these family members were experiencing.

d. <u>ICU Facilities for Families</u>

Families, particularly those who needed to be close to their relative, told us that the facilities for families in some ICUs were less than stellar:

> "*My husband would lay on the couches in the waiting room, but they are not comfortable. Fortunately he can sleep anywhere."* (C5)

Others had more positive experiences, agreeing with the patient who told us:

> *"I took a downturn at 11 pm at night and he came in and she (nurse) offered you a bed. Yes, she brought in a cot and blankets."* (C 3)

Families also told us of unpleasant experiences in the family waiting rooms:

> "*You want some time by yourself ... I went to the bathroom at one point, just to get away."* (S 2)

The waiting rooms were always busy and sometimes:

> *"It was like a whole crowd and they filled up the entire family waiting room and you would go in there at any time and they were sleeping all over the place ... but you felt you were... intruding. There's too many of them and only one of you and you felt out of place."* (S 3)

We were told that there were times when a quiet, private place to think, cry or just take a nap would be ideal. One participant, who knew where he would sit the quiet area, suggested:

> *"…a separate room for individuals with five loungers and anyone could come in and have that respite. You could section it off with a recliner in there like in a library to separate people a bit."* (CI 1)

Other suggestions for improving family facilities included providing a cart with water and snacks, free television, more control over the noise level of visitors, and a pleasant place to sit - not a waiting room - but more in the nature of a healing garden.

Category 5: Medical Care

Medical Care, the fifth and last major category, has two sub-categories:

a. Providing the Best Medical Care
b. Continuity of Staff

Participants appeared almost to take for granted that the medical care provided by physicians was of a uniform, exceptionally high standard. There appeared to be a sense that, this was Alberta and the quality of our intensivists was unquestioned. This category is the last prerequisite for providing a Community of Caring.

a. <u>Providing the Best Medical Care</u>

This was the most consistently positive sub-category with very clear praise for the high standard of medical care. Only one participant, who was from a regional centre, questioned the medical care:

> "*The doctor there ([…] ICU), I couldn't trust him any further than I could throw this table."* However, the participant went on to qualify her comments saying: "*I was air-lifted out of […] because they didn't have any ICU doctors then. I think the doctors that work outside the big urban settings … they're probably overworked."* (C 6)

She believed there were no specialist intensivists available at that ICU when she was a patient.

Apart from this single comment, no one appeared to doubt that the physicians were highly skilled and were working as diligently as possible with their critically ill patients. We consistently heard:

> "*The doctors were fantastic; I can't remember much in the ICU. All I could say is to give thanks to the doctors – they saved me* and *they were terrific" (C3).*
>
> "*I mean they saved his life twice. What can I say? They're terrific."* (CI 3)

Whether the patient lived or died, the praise for the standard of medical care remained high:

> "*My experience for the two weeks ... (was) that the level of care my son received during those two weeks and he was in a coma the whole time…was nothing short of exceptional."* (CI 1)

While participants expressed no doubt about the high standard of the medical care in ICU, some were less impressed with certain physicians' bedside manner and their ability to communicate with families. A husband whose wife had extensive multiple skull fractures and brain injury related:

> "O*ne of the intensivists was a really good teacher, but as far as bedside manner, he was, he didn't want to talk to me. It is really critical in ICU to have people who have the whole package." (C 17)*

Other comments such as a husband being consoled by a nurse, "*This is a really good doctor, but her bedside manner is sometimes…" (C 4)* and, "*You can tell by his bedside manner – he just* *wants to be done with you. I was glad when his seven days were up" (C 15),* were fairly isolated.

Generally physicians were praised for being approachable and trying to talk in lay terms:

> *"They (doctors) are there night and day and always doing rounds and if they saw you sitting they would always come in and say 'this is what we talked about this morning, this is what we are doing' ... these doctors are not only taking care of the patient, but are also concerned about, and taking care of the family."* (C 1)

b. Continuity of Staff

Continuity of staff was a major concern with respect to smooth delivery of medical care. Families were worried that information about the patient might not be transferred accurately, and also voiced concerns that it was difficult to develop relationships given high staff turnover. We commonly heard:

> "*The only problem was continuity of staff.*" (C16)
>
> *"One of the challenges I found in ICU ... is the lack of continuity. The only continuity I found was spiritual services."* (C17)
>
> *"They were constantly changing, apart from the unit clerk. To have someone stable there would be nice – you kind of dreaded the shift and doctor change."* (C10)

There was general agreement that passing information between shifts was an issue. The dilemma of continuity of care, family members becoming familiar with the staff caring for their relative and developing a comfortable, trusting relationship, did seem to hinder the development of A Community of Caring. It was notable that at least one regional centre seemed to have avoided this problem, possibly due to fewer staff members.

III. Post-ICU Experience

This last phase of the ICU journey had two categories:

1. Patient and Family Transition from ICU to Hospital Ward
2. Post-ICU Concerns When the Patient Is Home

Transition to a hospital ward is a multi-faceted topic, and, as the experience merits, will be explored in greater depth in a separate study. Therefore we will outline only the principal concerns. None of our participants discussed any referral to bereavement or trauma counseling. This topic is addressed in our recommendation section.

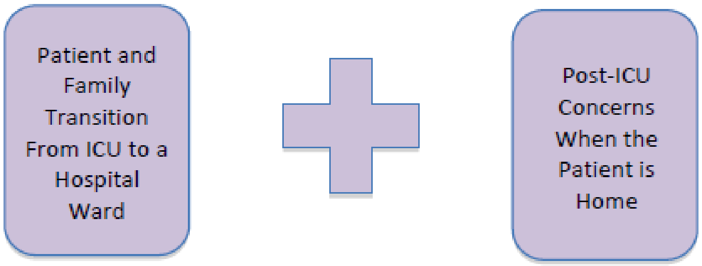

Figure 4. Post-ICU Experience.

1. <u>Patient and Family Transition From ICU to a Hospital Ward</u>

Patient and family members agreed that the transition from ICU to a hospital ward was an extremely traumatic experience:

> "*Going from ICU to that (ward) was a real culture shock"; "All the things you are not supposed to do in ICU, you are told on the ward, 'can't you do that for yourself?' ... I wasn't supposed to bend over and when I couldn't get my slipper on a nurse said 'well I guess you'll have to go without one.'"* (C 2)
>
> "*It was easier to leave him in ICU than when he was on the ward – you just knew someone was there taking care of him (in ICU*)." (C 5)

Some family members had problems contacting ward staff to get information:

> *"The biggest problem was the physician she was transferred to was not there ... for the best part of a month. Her office was giving either misleading information or incorrect information about whether she was here or not*." This husband was later told: "*ICU is perceived as a black hole – anything that goes in just disappears and nothing comes out."* (C 17)

2. <u>Post-ICU Concerns When the Patient is Home</u>

Some patients believed ICU should provide them with information about the longer term effects of some of medications used in ICU. We were told:

> "*I was hooked up to eight bags of intravenous at a time and I'm probably still impacted a lot by the medication I took ... there should be an information sheet for patients in terms of what to expect."* (S 5)

Other post-ICU concerns included patients feeling "stoned," hair loss, exhaustion, body rashes, memory lapse and gaps in time.

These experiences created anxiety for both families and patients; we heard that none of these problems had been mentioned or addressed in hospital. The participants saw providing information about possible longer term side effects of ICU administered drugs as an ICU responsibility. They believed that neither staff in the hospital wards nor family physicians had enough knowledge to provide this information. Participants stated: “*We need some indication of what you might notice. Be prepared for what might happen to you”* (Patients in the SET group).

Discussion

This patient engagement research study allowed the participants to determine the guiding questions we asked and the direction the study took. By including a group of participants to review, critique and organize the emerging themes, the participants were involved in co-creating the findings. The study was guided by patients and families who vocalized and discussed their experiences in ICU. It is notable that all of our participants were able to relate both positive and negative experiences, and all wanted to contribute to helping ICUs to become more patient and family-centred. They saw their participation as an opportunity to endorse what they found helpful and identify potential improvements. No single participant had an entirely negative experience.

The research findings conform to themes identified in previous studies, including; information, proximity to the patient, assurance, support and comfort. This study, however, represents confirmation from a patient and family perspective, allowing ICU administrators and staff access to a previously untapped resource. Patients and families told us in detail what interfered with having their needs met and were very clear that they depended on ICU staff to invite them into a trusting and comforting relationship. They were also clear that such relationships are extremely fragile. Trust can be broken by one negatively perceived action or statement, no matter what relationship had been previously built. Families believe they are back at square one – fearful, disoriented and mistrusting - just as they were when their relatives were admitted to ICU. The actions and behaviour of the staff must be consistent for families to feel welcomed, valued and respected. Patients and families perceive staff as a team and need all team members working together for them to feel confident in the ongoing service and support (see Figure 5).

In our literature review, we found that much of the responsibility for forging relationships with families was placed on the nurses’ shoulders. Our participants indicated they were very dependent on nurses and these interactions impacted family perceptions. However, both patients and families acknowledged how busy nurses were and that their main function was to care for the patients. They believed a separate person, versed in medical language, should be responsible for familiarizing them with ICU, listening to their concerns, explaining the rules and daily care procedures, and inviting their participation in caring for the patient and support them when necessary. These actions would alleviate their anxiety around “disturbing the nurses” and foster better relationships with all staff. There was a perception that working with families was an extra task that was undertaken when staff had the time or inclination rather than an important part of the overall service to patients and families. They also believed that any family liaison position should be consistent to allow for as much continuity of contact as possible. They saw this person as an interpreter, navigator, informant and supporter.

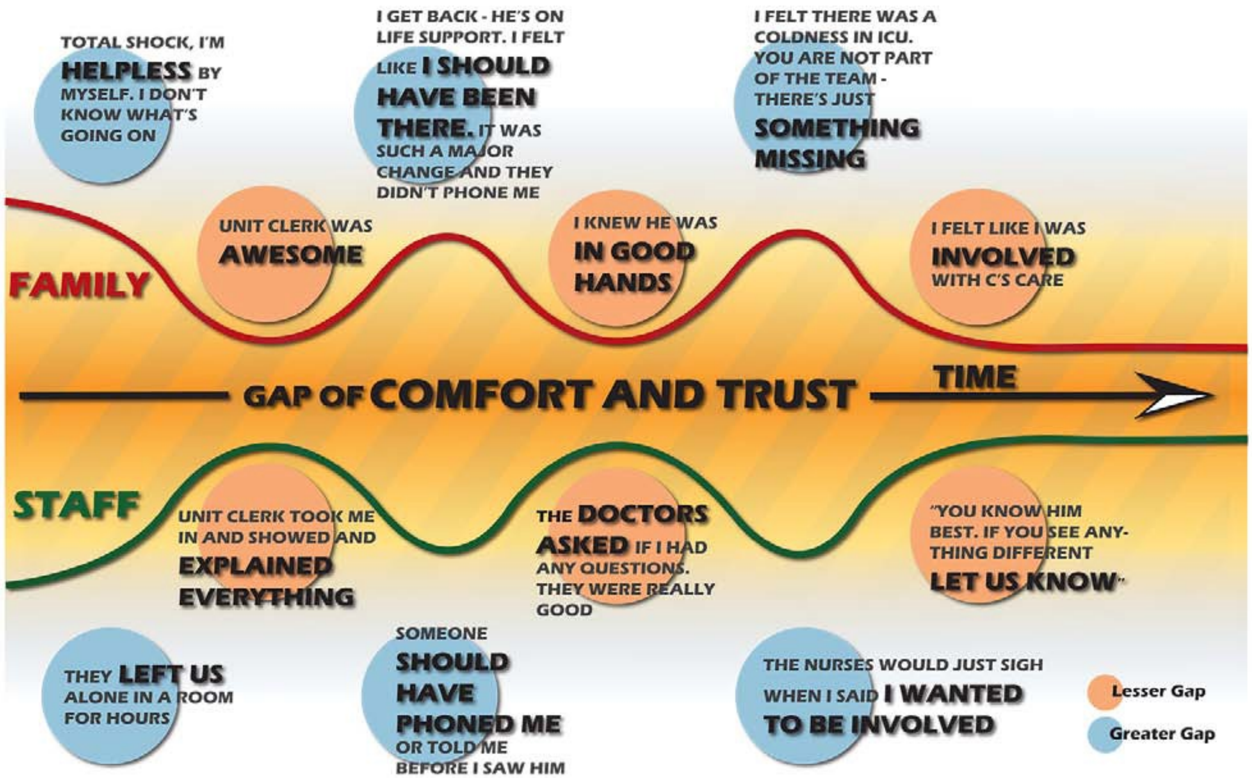

Figure 5: Patient and Family Zone of Comfort and Trust Over Time.

Our study differed from previous research as we identified Honouring Patients and Their Voices as the most important category to meet patient and family's needs. Our participants saw this as a fundamental requirement, the foundation of making the best of a stressful, fearful experience, and an underlying element in all the other categories. When the patient and family voice was consistently heard, patients and families felt they were well cared for, respected and valued. They became part of the care team; a community of caring supported by the culture in ICU and the excellence of the medical care.

Our findings concurred with other studies that cite communication as the key factor in developing and maintaining a patient and family-centred ICU. However, we found that it is not simply the ′what‘, but more importantly the ‘how‘ of such communication that truly fosters patient and family engagement. The patient's and family's perception of staff beliefs, behaviours and actions engenders the necessary comfort and trust emblematic of a patient and family-centred ICU. Families desire to be engaged and helpful, and need to be proactively engaged for this to happen successfully.

Strengths and Limitations

We used focus groups and individual interviews, a form of triangulation, increasing the credibility and trustworthiness of the data (Shenton, 2004). All facilitators have had ICU experience as close family members of a patient. This information was shared with the participants, who appeared to find this comforting, as they felt fellow patients and family members would better understand their experiences.

The absence of diverse ethnic groups is a limitation of the study. Any further study undertaken within Alberta should attempt to access a diverse population regardless of language difficulties. While this study includes participants from 13 ICUs across Alberta, as a result of geography and time limitations, some sites are represented by only one interview participant. Any further work should have more focus on the five regional ICU sites.

Recommendations

The following are the top five recommendations of patients and family members.

1. Thought should be given about providing dedicated team members to liaise with families on a consistent basis. This could be a social worker, ward clerk, chaplain, or designated nurse. It could be a family guide – someone with experience and ongoing availability who is interested in families and able to inform them about ICU practices and language. They would act as guides, navigators, and translators of medical terms as outlined within the findings. This would provide more stable family engagement with ICU.
2. Staff should be reminded about the fragility of family trust. Unfortunately, the vast majority of caring staff don’t make up for the very few who are brusque, inappropriate or leave families feeling a nuisance, vulnerable, fearful or not welcome.
3. Previous studies have stressed the importance of communication as a key factor in maintaining a patient and family-centred ICU. This study confirms this, and stresses the importance of the mode, tone and content of communication.
4. We also endorse our participants’ request that some type of information sheet summarizing the more common longer-term side effects of the drugs administered in ICU be provided to patients and families.
5. We believe the “Transition from ICU Study” is a vital component in understanding the difficulties of patient transfer out of ICU. We also recommend investigation of post-ICU trauma. Patient and family lives are often irrevocably affected by the critical illnesses treated in ICU. Thought might be given to an investigation of this phenomenon with a view to identifying those families who may need further help. This may take the form of timely trauma and/or bereavement counseling.

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